

Review

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The Stanford Health Assessment Questionnaire: Dimensions and Practical Applications

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Abstract

The ability to effectively measure health-related quality-of-life longitudinally is central to describing the impacts of disease, treatment, or other insults, including normal aging, upon the patient. Over the last two decades, assessment of patient health status has undergone a dramatic paradigm shift, evolving from a predominant reliance on biochemical and physical measurements, such as erythrocyte sedimentation rate, lipid profiles, or radiographs, to an emphasis upon health outcomes based on the patient's personal appreciation of their illness. The Health Assessment Questionnaire (HAQ), published in 1980, was among the first instruments based on generic, patient-centered dimensions. The HAQ was designed to represent a model of patient-oriented outcome assessment and has played a major role in many diverse areas such as prediction of successful aging, inversion of the therapeutic pyramid in rheumatoid arthritis (RA), quantification of NSAID gastropathy, development of risk factor models for osteoarthritis, and examination of mortality risks in RA.

Evidenced by its use over the past two decades in diverse settings, the HAQ has established itself as a valuable, effective, and sensitive tool for measurement of health status. It is available in more than 60 languages and is supported by a bibliography of more than 500 references. It has increased the credibility and use of validated self-report measurement techniques as a quantifiable set of hard data endpoints and has contributed to a new appreciation of outcome assessment. In this article, information regarding the HAQ's development, content, dissemination and reference sources for its uses, translations, and validations are provided.

Why assess Health-Related Quality of Life with the Health Assessment Questionnaire (HAQ)?

The ability to effectively measure health-related quality-of-life longitudinally is central to describing the impacts of disease, treatment, or other insults, including normal aging, upon the patient. Assessing these outcomes

requires instruments that are comprehensive, reliable, valid, responsive, and those that have been stable for a sufficient length of time to permit longitudinal study. Such measures are particularly significant in studies where short term results are not the primary outcomes of interest, but can be of use over periods as short as six weeks.

The HAQ is one of the most widely used comprehensive, validated, patient-oriented outcome assessment instruments. It has been administered by the Stanford Arthritis, Rheumatism, and Aging Medical Information System (ARAMIS) more than 200,000 times to assess clinical status, evaluate effectiveness in clinical and observational trials, and to define health outcomes, and it is sanctioned by the American College of Rheumatology for assessing physical function in rheumatoid arthritis trials[1,2]. It is available in more than 60 languages and is supported by a bibliography of more than 500 references.

What is the HAQ?

The HAQ is one of the first instruments deliberately designed to capture prospectively and by protocol the long term influence of multiple chronic illnesses and to allow supplementation by additional measures for particular studies. The HAQ has played an influential role in establishing health outcome assessment as a quantifiable set of reliable, valid and responsive hard data points.

Because the HAQ emanated from the rheumatology field, it sometimes has been characterized as a "disease-specific" instrument rather than having been adjudicated on the basis of its structure, content, and history of use. The HAQ has been and continues to be administered across diverse disciplines and in different cultures, with properly designed adaptations that do not impact its reliability and validity. It should be considered a "generic" rather than a "disease-specific" instrument, since it assesses the dimensions of death, disability, drug side effects, discomfort, and economic costs, none of which are "disease-specific".

What areas of health does the HAQ measure?

The HAQ is typically used in one of two formats. The full HAQ collects data on five generic patient-centered health dimensions: (1) to avoid disability; (2) to be free of pain and discomfort; (3) to avoid adverse treatment effects; (4) to keep dollar costs of treatment low; and (5) to postpone death [3–6]. It includes sections on drug side effects and medical costs, as well as supplemental sections on demographics, lifestyle and health behaviors. However, the version that has received the widest attention, most frequent use, and what is commonly referred to in the literature as "the HAQ," is the "short" or "2-page" HAQ. The 2-page HAQ contains the HAQ Disability Index (HAQ-DI), the HAQ visual analog (VAS) pain scale, and the VAS patient global health scale; [see Additional file: 1 HAQ Questionnaire.pdf for a copy of the English version of the questionnaire].

As with any instrument, the HAQ has limitations, and as generally used, does not capture disability associated with sensory organ dysfunction or psychiatric dysfunction and does not directly measure patient satisfaction or social

networking. Yet these variables, or other variables of interest to the user, can be readily appended.

The HAQ Disability Index (HAQ-DI). The disability assessment component of the HAQ, the HAQ-DI, assesses a patient's level of functional ability and includes questions of fine movements of the upper extremity, locomotor activities of the lower extremity, and activities that involve both upper and lower extremities. There are 20 questions in eight categories of functioning which represent a comprehensive set of functional activities – dressing, rising, eating, walking, hygiene, reach, grip, and usual activities. The stem of each item asks over the past week "Are you able to ..." perform a particular task. The patient's responses are made on a scale from zero (no disability) to three (completely disabled). Each category contains at least two specific component questions (See Additional File 1_2-page HAQ Questionnaire.pdf for a copy of the English version of the HAQ-DI).

The HAQ VAS Pain Scale. The HAQ pain scale is designed to assess the presence or absence of arthritis-related pain and its severity. The objective is to obtain information from patients on how their pain has usually been over the past week, even though pain may be reported to vary over the course of a day or from day to day. The HAQ pain scale consists of a doubly anchored, horizontal VAS, that is scored from zero (no pain) to three (severe pain), or alternatively from 0 (no pain) to 100 (severe pain). The VAS for pain has been used widely in experimental, observational, and clinical settings [7–12].

Other Dimensions of the Full HAQ. Drug toxicity data collected by the full HAQ include the drug, dosage, time on drug, specific side effects, degree of severity, the importance to the patient, and subsequent drug course, i.e., whether or not the drug was discontinued due to the side effect. HAQ-derived drug side effect data has permitted the development of a summary Toxicity Index (TI) that quantifies the magnitude of adverse effects (toxicity) associated with specific medications [11,13,14]. The TI is a first attempt to quantitatively describe the overall toxicity of medication. Prior adverse effect assessments had used variables comprised of the percentage of patients discontinuing the drug because of side effects or had presented comparative frequencies of selected individual side effects.

Direct cost data that include physician visits, hospital days, laboratory costs, x-rays, medications, and other medical costs including use of alternative treatments and procedures, and indirect cost data due to loss of productivity are captured by the full HAQ.

Death, while obviously not a self-report outcome on the HAQ, is a requisite part of the conceptual model of patient outcome. In this HAQ dimension, mortality-related data, causes, and date of death, are obtained via search of the United States National Death Index.

Both the 2-page and full HAQ contain the HAQ VAS patient global health status scale. It is among the common VAS instruments, which include the Torrance "feeling thermometer" in the EuroQol instrument and the VAS in the Arthritis Impact Measurement Scales, both of which are used to measure quality of life. The HAQ global health status scale is a 15 cm doubly-anchored horizontal VAS that is scored from zero (very well) to 100 (very poor) and has been validated as a measure of quality of life. Fries and Ramey [15] compared the HAQ global to the Torrance quality-of-life "feeling thermometer" and found the two scales to be highly correlated ($r = -0.676$; $p < 0.001$), indicating that both instruments are measuring similar quality of life constructs.

How was the HAQ developed?

The Health Assessment Questionnaire (HAQ) was originally developed in 1978 by James F. Fries, MD, and colleagues at Stanford University. The HAQ Disability Index (HAQ-DI), the original HAQ section to be developed and validated, was initially developed under the auspices of the Stanford Arthritis Center. It recognized the importance of the original American Rheumatism Association functional class measure [16] and also the lack of sensitivity to change of that four-category measure. The HAQ-DI was developed by parsing questions and components from a variety of instruments extant at the time, and evolved over numerous iterations through a series of subjective and objective assessments via statistical evaluation, physician appraisal, and patient feedback [17].

The components of the 2-page HAQ (the HAQ-DI, pain scale, and global health status scale) have retained their original content and format since the early 1980s, while the remaining dimensions in the full HAQ are periodically tailored and supplemented with additional questions when contemporary issues arise for specific hypotheses or research questions by ARAMIS or other investigators.

How was the HAQ validated?

The disability index of the HAQ (HAQ-DI) has been validated in numerous studies and disciplines. It has been shown repeatedly to possess face and content validity via comparison with other instruments in multiple disease conditions. The construct/convergent validity, predictive validity, and sensitivity to change have also been established in numerous observational studies and clinical trials. The HAQ-DI has also demonstrated a high level of

convergent validity based on the pattern of correlations with other clinical and laboratory measures [2,11,17–19]. Validity of the HAQ pain scale and the global health status scale have also been demonstrated in numerous studies [2,11].

In which populations has the HAQ been used?

The full HAQ has been deployed in studies with HIV/AIDS patients, normal aging populations, adults and children with rheumatic diseases, and in disabled workers [2,20–22]. It has been employed in population-based studies, including the follow-up to the National Health and Nutrition Examination Survey (NHANES) [23]. It has also been applied to a variety of diseases and conditions, including osteoarthritis, juvenile rheumatoid arthritis, systemic lupus erythematosus, ankylosing spondylitis, fibromyalgia, psoriatic arthritis, systemic sclerosis and has been adapted in many languages for adults as well as children [2].

What translations are available?

The HAQ Disability Index (HAQ-DI) was originally developed and validated for English-speaking populations in the United States and Canada. It has since been translated or culturally adapted into more than 60 different languages or dialects, often with only minor changes. Table 1 presents a resource listing of translations since 2002. Translations and cultural adaptations of the HAQ-DI are usually carried out by administering investigators. Many have also been performed by the MAPI Research Institute in Lyon, France, and the Health Outcomes Group in Palo Alto, California, both of which have had extensive experience in translating and culturally validating the HAQ-DI; fees are sometimes charged by these vendors.

Translated HAQ-DIs have generally been fully validated, using methods such as test-retest reliability, item-total correlations, convergent validity, interviewer vs. self-administered formats, and factor analyses. Translations are subsequently back-translated by a different translator, and the two English versions compared. This process is repeated until coherence is achieved. To date, culturally adapted HAQ-DI instruments have proved as equally reliable and valid as their parent. To adapt the HAQ-DI culturally, modifications of individual items have sometimes been necessary. The types of items most frequently in need of adaptation have included colloquial expressions or those for which names or types of items or utensils are culturally idiosyncratic. For example, some Asian cultures do not consume milk in cartons; thus, an appropriate substitution in keeping with the original intent of the item is made. In some European countries a bathtub is much more commonly used than is a shower, requiring question modification.

Table 1: Translations and Cultural Adaptations of the Adult Health Assessment Questionnaire (HAQ) and the Childhood Health Assessment Questionnaire (CHAQ)

NOTE: References for independent translations are found in Bruce B, Fries JF. The Stanford health assessment questionnaire (HAQ): a review of its history, issues, progress, and documentation. *J Rheumatol.* 2003;30(1):167–78. Table adapted and used by permission of the Journal of Rheumatology.

Independent translations:

HAQ: Arabic, Australian, Austrian, Chinese, Finnish, French (France), German, Italian, Korean, Netherlands, Norwegian, Portuguese (Brazil, Portugal), Scandinavian (multiple languages), Scottish, Spanish (Mexican, Chilean European, Costa Rican, Argentinian), Swedish, Swiss, Thai, Turkish.

CHAQ: Austrian, Bulgarian, Croatian, Danish, Dutch, Czechoslovakian, English (British), Finnish, Belgian-Flemish, French (France), Georgian, German, Greek, Hebrew, Hungarian, Italian, Latvian, Korean, Netherlands, Polish, Portuguese (Brazil), Russian, Serbian, Slovakian, Spanish (Argentinian, Castilian, Costa Rican, Mexican), Swiss-German and Swiss-French, Turkish.

Translations/adaptations available through the Health Outcomes Group (E-mail: HOG_USA@Compuserve.com):

Australian, Austrian, Belgian Dutch (Flemish), Belgian French, Canadian (French), Chinese (Cantonese [Hong Kong]), Croatian, Danish, English (Canadian, United Kingdom), Finnish, French (France), German (Germany, Switzerland), Greek, Israel (English), Hebrew, Italian, Lithuanian, Portuguese (Brazil, Portugal), Romanian, Singapore (English, Malay, Mandarin), Slovenian, So. Africa (Afrikaans, English), Spanish (Argentinian, Chilean, Columbian, Costa Rican, Guatemalan, Peruvian, Spain, United States, Venezuelan), Swedish, Turkish.

Translations/adaptations available through the MAPI Institute (website: <http://www.mapi-research-inst.com>):

Australian, Austrian (German), Belgian Dutch (Flemish), Belgian French (Walloon), Canadian (French), Czech Republic, Danish, Dutch, English (Canadian, India, New Zealand, United Kingdom), Finnish, French (France), German, Greek, Hebrew, Hungarian, Israel, Italian, Japanese, Norwegian, Polish, Portuguese (Brazil), Russian, Slovak Republic, So. Africa (Afrikaans, English), Spanish (Argentinian, Costa Rican, Guatemalan, Mexican, Spain, Venezuelan), Swedish.

How is the HAQ administered and how long does it take?

The HAQ is usually self-administered, but can also be given face-to-face in a clinical setting or in a telephone interview format by trained outcome assessors, and has been validated in all of these settings. The questionnaire is typically mailed to patients every six months, who are asked to complete it without additional instructions. Patients usually find that the 2-page HAQ is entirely self-explanatory, and clarifications are seldom required. Follow-up phone calls are sometimes needed to obtain missing data or to clarify ambiguous responses in the high-quality research data applications. The HAQ disability index and pain scale can be completed in approximately five minutes. The full HAQ takes 20 to 30 minutes to complete.

How is the HAQ Disability Index (HAQ-DI) and pain scale scored?

The HAQ-DI indicates the extent of the respondent's functional ability, is sensitive to change, and is a good predictor of future disability and costs. It assesses a patient's usual abilities using their usual equipment during the past week. Scoring of the HAQ-DI is patterned after the American Rheumatism Association/American College of Rheumatology functional classes [16,24]. For each item, there is a four-level difficulty scale that is scored from 0 to 3, representing normal (no difficulty) (0), some difficulty (1), much difficulty (2), and unable to do (3). There are 20 questions in eight categories of functioning – dressing, rising, eating, walking, hygiene, reach, grip, and usual activities. The highest component score in each category determines the score for the category, unless aids or

devices are required. Dependence on equipment or physical assistance increases a lower score to the level of 2 to more accurately represent underlying disability. A complementary scoring method ignores scores for aids and devices when computing the category scores and represents residual disability after compensatory efforts. The eight category scores are averaged into an overall HAQ-DI score on a scale from zero (no disability) to three (completely disabled). The scale is not truly continuous but has 25 possible values (i.e., 0, 0.125, 0.250, 0.375 ... 3). The HAQ-DI score is not computed when the patient provides answers in fewer than six categories. When the HAQ-DI is used to assess disability in a specific disease or condition, usually a single word change can be made in the stem to identify the condition [25,26], which does not change scoring. Disability as measured by the HAQ-DI repeatedly has been correlated with mortality rates, progression of aging, and health care resource utilization [25, 57, 135, 181]. For additional information regarding scoring and analysis, please refer to the ARAMIS website, <http://aramis.stanford.edu>, and Bruce B and Fries JF, The Stanford Health Assessment Questionnaire (HAQ): A Review of Its History, Issues, Progress, and Documentation. *J Rheumatol.* 2003;30(1):167–78.

The HAQ pain scale is designed to obtain data relative to the presence or absence of arthritis-related pain and its severity. The objective is to obtain information from patients on how their pain has usually been over the past week, even though pain may be reported to vary over the course of a day or from day to day. Complete scoring directions are available at the ARAMIS website, <http://aramis.stanford.edu>.

How are the HAQ-DI scores interpreted?

Scores of 0 to 1 are generally considered to represent mild to moderate difficulty, 1 to 2 moderate to severe disability, and 2 to 3 severe to very severe disability. Average scores that have been reported in a population-based study are 0.49, and in osteoarthritis and rheumatoid arthritis patients are 0.8 and 1.2, respectively. For additional references regarding score interpretation, please see Bruce B and Fries JF, The Stanford Health Assessment Questionnaire (HAQ): A Review of Its History, Issues, Progress, and Documentation. *J Rheumatol*. 2003;30(1):167-78.

Is the HAQ-DI responsive to change? What is a meaningful change for the HAQ-DI score?

The HAQ-DI is very responsive to change, and usually is the most sensitive to change of the available outcome measures. It is used in the overwhelming majority of studies of rheumatoid arthritis and recommended by the United States Food and Drug Administration and the American College of Rheumatology. Some investigators have suggested that the Minimal Clinical Important Difference is 0.22; others have maintained that 0.10 or thereabouts is clinically important. Additional references may be found in Bruce and Fries, The Stanford Health Assessment Questionnaire (HAQ): A Review of Its History, Issues, Progress, and Documentation. *J Rheumatol*. 2003;30(1):167-78.

What is the availability and cost of using the HAQ?

The HAQ is copyrighted by Stanford University for the purpose of insuring that it will be used unmodified to preserve the validity of its results and contribute to standardization of assessment across studies. However, it is considered to be in the public domain, with the request that users cite relevant HAQ articles(s) in their publications. There is no charge from Stanford for permission to use the English version of the HAQ. However, other groups that have independently translated the HAQ may charge for their versions.

Who may I contact (Email, fax and phone) to obtain a copy of HAQ?

Judy Rechsteiner, Administrative Assistant

E-mail: trex@stanford.edu

Fax: 650/723-9656

Phone: 650/725-4612

How can we obtain more information about the HAQ?

Please go to the ARAMIS website at <http://aramis.stanford.edu>.

Conclusions

Collection of longitudinal patient outcome data, based on the five patient-centered dimensions, is increasingly standard in clinical trials, epidemiologic studies, and in patient care, representing a major paradigm shift over the past two decades. The HAQ has increased the credibility and use of comprehensive measurement techniques involving validated patient self-report and has led to a new appreciation of outcome assessment. Outcome measurement is rapidly increasing in use, and we anticipate increased focus on a smaller number of instruments with supplemental questions used for disease or study-specific queries. We believe the HAQ to have appropriate attributes to be among those considered for use as standard instruments.

Acknowledgements

Some content and Table 1 adapted from and Bruce B and Fries JF [2] and are used with permission from the Journal of Rheumatology.

Additional material

Additional file 1

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[<http://www.biomedcentral.com/content/supplementary/1477-7525-1-20-S1.pdf>]

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